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ABSTRACT

This issue of the newsletter offers suggestions to help parents improve the experience of living with a handicapped child during the out-of-school summer months. Maintaining a moderately structured schedule is recommended, with activities based on the child's individual interests and energy level. Participation in routine activities at home (e.g., sorting laundry, pouring juice) can enhance self-esteem and build independent living skills. Sleepovers at home build social skills. Low-key day trips, weekend vacations, and travel tips for longer trips are discussed. A final section lists do's and don'ts, including allowing the child to participate in decision making, starting activities early in the day, and not pressuring the child to compete. (JW)

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Special Parent ★ Special Child ★

Practical pointers for parenting handicapped children

VOL. 3, NO. 4

JULY/AUGUST 1987

SCHOOL'S OUT!

**A survival guide to
summer with your
special child**

A successful summer should include something for everyone. Longer days, with freedom from the pressures of work and school, can benefit the entire family. Ideally, summer is the time to relax, a time when your special child and his siblings can stretch their imaginations, develop new hobbies, revive interests and improve life skills. Family trips and outings are good ways to increase a sense of togetherness and store up memories of good times spent together. If, however, summer to you means idle hours and frazzled tempers, then this issue will show you how to make this vacation better than any before.

A structured summer or not?

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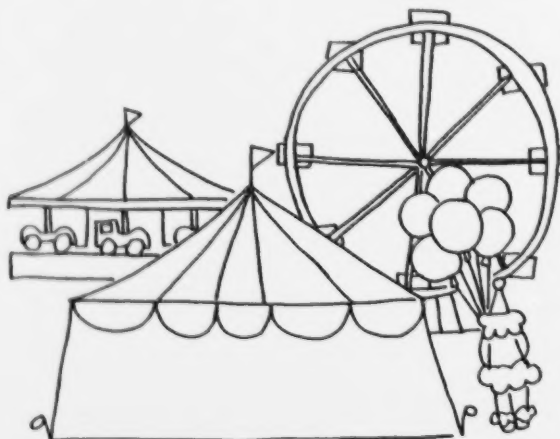
Most special children feel threatened when days are left totally unstructured. They react with whining, boredom and have a tendency to bother others, especially siblings. While it's not necessary to duplicate the routine of a school day, it's best to maintain a moderate schedule of activities. Although wake-up and

bedtime can be flexible, it's a good idea to keep mealtimes, bath and storytime on an approximate schedule. All children, special or not, need a careful blend of structured activities such as swimming lessons or day camp, coupled with enough spare time to relax—even just to watch the flowers grow.

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Know your child

Each special child is unique with his own needs, wants, limitations. If, for instance, your special youngster is overactive, he is going to require more structured physical activities to burn off excess energy. Include swimming sessions or go jogging or biking on a daily basis to help your youngster channel his energies.

If, on the other hand, your special child is withdrawn or unsure of himself in competitive situations, he should be encouraged to develop his talents in other ways. Perhaps he has an untapped flair for drawing or model-making. Explore these alternatives with him; a new interest or hobby is an excellent way of raising your special youngster's self-esteem.

Your home can be a learning center

Summer is a good time to try some learning-while-doing activities that will help sharpen your special child's independent living skills. Teaching your special youngster how to sort laundry, load a dishwasher, pour juice, or help prepare a picnic lunch for the family are invaluable ways to enhance his sense of self-worth

and family participation. It's best to figure out beforehand how to demonstrate these tasks step-by-step. Make sure your special child has mastered each step before going on to a more complicated one and remember to praise his efforts no matter how inefficient he may be at first.

Make the most of leisure time

The slower pace of a summer's day is a perfect time to encourage your special child to do more things for himself. What does it matter if it takes close to an hour for him to dress himself or make his own bed? There's no school bus honking at the door. Of course it's tempting for you to do

these things for him but even if simple tasks take much longer, allow ample time to practice. Don't deny him the precious feeling of accomplishment that comes with mastery. Although initially it may be difficult to watch your youngster struggle, it's well worth the effort.



ABOUT SPECIAL PARENT/SPECIAL CHILD:

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Plan a sleepover

Summer means an increase in social gatherings and this can include inviting a playmate over, having him stay for supper and, because there's no school the next day, spending the night. Sleepovers are important; they broaden your special child's ability to socialize with others and normalize his overall experiences. There is also the likelihood that sleepover arrangements will be reciprocated. This will enhance your youngster's ability to separate from you and is an excellent means of fostering independence. The sleepover ex-

perience can gradually be extended to include a weekend with friends, relatives or grandparents and is an excellent way to prepare your special child for a summer sleep-away camp. Always include a favorite toy or other familiar objects in his overnight bag and make sure that he knows when and where he is to be picked up and taken home.

Remember that these short-term separations are mutually beneficial, for you get a respite from total care while your special child increases his bid for independence.

Travel tips



Family vacations needn't be lengthy, costly or complicated. Start out simply. In fact, it may be much less stressful for you and your special youngster if you begin with a low-key trip, close to home and of short duration. Many special children react adversely if they are in strange surroundings, especially for too long a time. However, with some creative thinking it is possible to plan day or short weekend trips that will intrigue and please the entire family.

Day trips. It might be fun to take a train ride from a nearby railroad station (or bus if no railway is convenient). Even going two or three stops away, getting off and exploring an unfamiliar town can be very exciting. Have lunch in a restaurant; lunch hours are often less crowded and less expensive than dinner out. Add some adventure to the excursion by not telling the family where you are going beforehand.

"Mystery" rides. Even an ordinary car ride can become a memorable experience if you add an element of surprise by calling it a "mystery" ride. Give your special child and his siblings some clues but don't tell them your final destination. Hand out a map for them to follow; this will sharpen school-related map skills as well as heighten their interest. End up at a different place than your usual routine excursions—perhaps your old hometown or school (if it's within a day's drive), a boatyard to watch the fishermen come in, a beach you've never visited, perhaps a town you've never seen. Plan a picnic supper or barbecue to complete the day.

Stop along the way. There's no reason to keep up a fast pace when it's a leisurely day trip close to home. Encourage your special child to pick a flower for pressing or collect some interesting rocks. Go hunting for old bottles or collect items for a collage. Take some photos for an album that will feature this particular day. Believe it or not—that's how memories are made.



Try a camp-out in your own backyard. This is ideal if you intend to go camping in a state park or local campground at some later date. Pitch a tent in your backyard, build a campfire, toast marshmallows and spend some time stargazing, if you wish. You can try out your sleeping bags—a good idea for first-time campers.

These dry-run experiences are helpful for your special child because they alleviate the stress of being in a strange environment.

Discover your own neighborhood. Have you visited the sights in your own hometown that others might have traveled great distances to see? How many native New Yorkers, for instance, have never seen the Statue of

Liberty? Often we rush pell-mell to get away from home, ignoring many fascinating activities in our own locale. Contact your local travel agent, Chamber of Commerce or visitors' convention or your state or regional tourist bureau for brochures about local points of interest and schedules of special events such as:

- state, local fairs or circuses
- craft fairs and demonstrations
- art shows, exhibits, fireworks
- horse and buggy rides, hay rides, historic railroads
- ferry or riverboat excursions
- day fishing trips
- walking tours, nature hikes
- seasonal museums and restorations.

Mini-vacations

ABOUT THE AUTHORS

Linda Murphy, M.S., is the founder and for the past 15 years has been the director of a widely known, approved school for mentally handicapped children serving children ages 5-21 in Westchester County, NY, and surrounding areas. A lecturer, teacher and administrator, she is a foster parent and the parent of a handicapped child, too.

Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.

If day-tripping with your special child has proved successful, you might want to extend the vacation to include a mini-trip. These short-term vacations are often more refreshing and less stressful than long trips which are generally complicated by much packing and planning.

The city weekend escape. If you are fortunate enough to live close to a good sized city, investigate city-based weekend package deals. Many fine city hotels have bargain weekend rates that often include lowered rates for children, complimentary breakfasts and bargain priced theatre tickets and sightseeing excursions. Call ahead and find out if qualified babysitting service can be arranged so that you and your spouse have time for some

grown-up entertainment or just dinner together in the hotel restaurant. If restaurant dining for every meal is too overwhelming for your special child and his siblings, try room service! It can be a memorable treat for everyone. Even a simple hamburger becomes a festive meal when it is wheeled in on a linen-covered trolley.

The four-day weekend. Renting a mobile-type of vehicle may be an ideal solution if you wish to visit nearby state parks, campgrounds or even see relatives without intruding on them too much. A mobile recreational vehicle usually has a compact kitchen, shower and four or more bunk-style beds on board. Look in your telephone yellow pages under "Recreational vehicles, renting and leasing" for more information.

Travel tips for longer trips

Although longer trips take coordination and planning, they are well worth the extra effort if in the end they refresh and revitalize the entire family. If, for any reason, your special child has behavior or nighttime restlessness that complicates overnight stays in hotels or visits with relatives, **why not rent** a lakeside cottage or mountain cabin, for example? The entire family would probably enjoy the change of scenery. Often state offices of tourism have brochures or lists of inexpensive cottages that are available at weekly rates.



Broaden your child's horizons. In all probability your special youngster has a limited concept of the world. You can increase his general knowledge and his grasp of geography by going over maps that show your travel route. Visit the library with him and take out books and National Geographic magazines, for instance, that will have photographs of the place you intend to visit. This will involve him with the actual travel plans and will heighten his sense of participation.

Travel agents usually can give you pamphlets and travel brochures that your special child can keep for a scrapbook. Perhaps there are movies or travelogues you can watch that will spark your youngster's interest and broaden his understanding.

Expect the unexpected. Make sure your special child knows what is going to occur beforehand (i.e. a plane ride, a car ride of several hours duration). Since most special children can't change gears easily, prepare him as best you can for the unexpected. Planes are frequently delayed or cancelled, cars break down, lug-

gage gets lost. Have a contingency plan—extra food and chilled juices in an insulated bag, emergency flares if you are traveling by car, a special carry-on bag with different games and activities to entertain your special child if you are experiencing airline delays or long waits. Whenever you can, arrive early to avoid last minute dashes and crowded waiting rooms. This is irritating to everyone, most of all to special children who tend to be extra sensitive to the noises of crowds and confusing settings.

Quit while you're ahead. It's a good idea to limit sightseeing excursions and other daytime activities. Too much going on in one day is apt to be overtiring for your special child. Leave the theme park, for example, **before** exhaustion sets in; return the next day, preferably in the morning when you are both rested and refreshed. By the same token, return home a day or two early. This will give the whole family a chance to wind down and readjust to the at-home routine.

Find time for yourself. We all need a rest and we all need an opportunity to get away. Some special parents feel guilty if their plans don't include all their children all the time. The guilt is undeserved. Time away from all your children allows you to unwind and, in the long run, makes you more effective parents.



Do's and Don'ts



- **Do remember that summer fun can be erased** if you pressure your special child to compete in activities that should be pursued just for fun. Encourage your special child to learn how to swim or horseback ride, but don't make unreasonable demands for life-saving certificates or blue ribbons.

- **Do seek out leisure-time activities geared to your child's special needs.** Now's the time to investigate if your area has special education recreation day camps or scout troops equipped to meet the needs of the handicapped. In many towns you will find scout councils ready to assist you in starting such a troop if one doesn't already exist.

- **Don't compare your special child's** summer activities unfavorably with his normal siblings'. This lowers his self-confidence unnecessarily.

- **Do permit your special youngster** to choose some of his favorite activities. Allow him to participate in the decision of where to go and what to do. This will enhance his sense of self-esteem.

- **Do remember to praise your special child when he behaves.** Too often we take notice only when our child whines, draws attention to himself or otherwise misbehaves in public. Taking the time to praise your youngster for being good **when he is behaving** eliminates much inappropriate attention-seeking behavior. This is especially important when you are with your special child in restaurants, hotels, etc.

- **Don't overdo it.** Driving hundreds of miles per day, for example, is too grueling. Make sure you stop early enough in the day to relax, perhaps swim or have a leisurely dinner before turning in.

Stopping **before** everyone becomes overtired will avoid the grouchy behavior that can ruin the day.

- **Do get an early start.** Most special children are fresher, more alert and do best in the early part of the day.

- **Do take along a Polaroid camera.** They are easy to operate and provide an instant reinforcement of the event. You can even bring along a photo album for your special child to paste the snapshots in while you go.

- **Do take along a first aid kit and any medication** your special child needs in a clearly identifiable prescription bottle. If your child has a chronic condition, make sure to consult with his doctor before you leave. In most cases your special child's pediatrician can give you information on where to obtain emergency treatment at your vacation locale if necessary.

- **Do pack a clearly recognizable carry-on bag or backpack** for each of your children no matter where you go. Inside be sure to include a familiar toy, games, activities or books geared for each child and individual snack items or favorite foods. Having their own individualized bag will avoid squabbling over each other's possessions.

- **Do provide an identification tag or bracelet for your special child,** especially if you plan to visit theme parks or other crowded places. Your special child's name tag should include name, home address, phone number of where you are currently staying and pertinent emergency information including any medication your special child requires.

PARENT-TO-PARENT

From time to time the editors would like to share with our readers news of parent support groups throughout the country who are providing outstanding service. This issue we are highlighting **Pilot Parents of Central Minnesota**.

It can be hard to accept that your child has a special need. Parents often feel isolated, frightened, confused and overwhelmed. A Pilot Parent is proof that you are not alone.

Pilot Parents of Central Minnesota is an organization that provides one-to-one supportive services and information to parents of children diagnosed with special needs.

Pilot Parents are trained volunteer parents who have experienced the heartbreak and joy of having a special needs child. They have no "magic" answers, but are willing to listen to and help other parents deal with the feelings and frustrations that often occur when a child has special needs.

Although Pilot Parents are not professionals, they have been carefully trained and screened and they can offer practical suggestions for meeting the daily challenges of caring for a child. Most of all they can help parents recognize their own needs and encourage them to face the future with realistic hope.

Parents who have a child with . . .

a physical impairment,
a mental handicap,
a chronic medical condition,
a terminal illness,
a learning disability,
an emotional problem,
or **any** special need . . .



and who would like to talk to a parent with a similar experience, or who know of someone who can benefit from the support of an "experienced" parent, can contact Pilot Parents. Referrals can be made by anyone—physicians, social workers, teachers, clergy, family, friends or parents themselves.

The parent must consent to a Pilot Parent contact before a match is made. Parent matches are made by the child's special need, family situation and personal experience. The Pilot Parent calls within 48 hours of accepting the referral and notifies the coordinator that contact has been established. The program and its participants are evaluated through a phone interview with the client 3-5 months after the match has been made.

Besides emotional support and understanding, Pilot Parent offers:

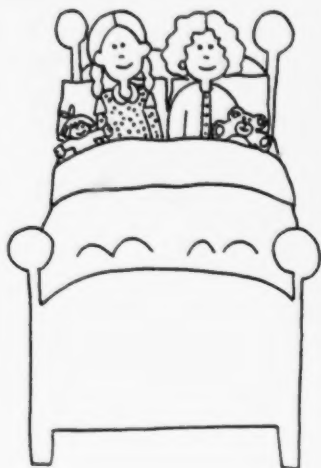
- factual information about a variety of special needs
- information about services, educational programs, and support and advocacy agencies
- introduction and access to people and groups with common concerns and interests

Pilot Parents of Central Minnesota is sponsored jointly by the Association for Retarded Citizens-Region 7, West Central Epilepsy Foundation and United Cerebral Palsy of Central Minnesota.

For more information, contact Pilot Parents of Central Minnesota, Terri Wolak, Director, at (612) 259-4032.

Psychologist's corner: QUESTIONS READERS ASK

by George Popper, Ph. D.



QUESTIONS AND ANSWERS

We invite inquiries or hints from our readers. If you have a question, a problem or comment about any aspect of parenting special children, write to:

Special Parent/Special Child
Lindell Press, Inc.
P.O. Box 462
South Salem, NY 10590

Q. "My husband insists that it's OK for him to take our 12-year-old son camping and leave behind our other son who is 10 and has cerebral palsy. I say that we should all vacation together or not go anywhere. This is causing such a problem in our family that I need some help."

A. From your description, it sounds as though your husband has difficulty accepting that he has a handicapped son. Perhaps he fears that your handicapped child might be injured on the trip. It is important to discuss these fears so they can be handled realistically, possibly including your 12-year-old son in the discussions. Many campgrounds are designed for family camping and have barrier-free facilities. Obviously, a child with cerebral palsy is at greater risk for injury and adds responsibilities for the parents. This does not mean, however, that a child with such a handicap should not be given every opportunity to learn and enjoy the same things we all do. The risks can be minimized with careful planning; such a trip can be a rewarding experience for all.

This does not rule out a short expedition with your 12-year-old son and his father to pursue something like strenuous mountaineering that is clearly beyond your special child's capabilities. Perhaps you can plan a special trip later on with just your handicapped son so that he does not feel left out.

Q. "My daughter, age 11, is very embarrassed about her mentally retarded 7-year-old sister. She wants to have a slumber party this summer but is worried that her sister will annoy her friends.

We want our daughter to have fun, but we know how bothersome our special daughter can get. Any suggestions?"

A. Your older child is entitled to a certain amount of privacy and should be allowed to have her friends over without interference from her younger sister. Certainly she should not be ashamed of her sister. I'm assuming she's not and that her friends already know that the 7-year-old is retarded. One way to deal with this situation is to allow **both** of your children to have friends over or to have your retarded daughter spend the night with one of her friends or relatives. Some advanced planning and careful supervision will be needed. In any case, one event should not interfere with the other.

Q. "We would like to take our physically handicapped daughter on family vacations. Are there any guides to state parks and hotels with wheelchair access?"

A. Yes, this information is readily available. Large chain hotels usually list specific available facilities in their brochures. Individual state offices of tourism, a travel agent, bookstores or your local library can also provide you with needed information. You may want to consult:

Society for the Advancement of
Travel for the Handicapped
26 Court Street
Brooklyn, NY 11242
(718) 858-5483

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